NGO COMMITTEE FOR
RARE DISEASES

The European Experience

Avril Daly

CEO Retina International

Vice President EURORDIS

A Committee of **CoNGO**

CoNGO
The Conference of NGOs
in Consultative Relationship
with the United Nations

Key Policy Achievements at EU Level

- The adoption of the EU Regulation on Orphan Medicinal Products in 1999
- The adoption of the EU Commission Communication on Rare Diseases in 2008
- The adoption of the EU Council Recommendation on European Action for Rare Diseases in 2009
- The adoption of the EU Directive on Patients' Right to Cross-Border Healthcare in 2011

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Maintaining Rare Diseases as a Priority

Continued Policy Engagement at EU Level

- The promotion and maintenance of rare diseases as:
  - EU Public Health Policy priority
  - EU Research Framework Programme priority
- The Promotion of National Plans and Strategies on Rare Diseases in EU Member States and beyond
- Contribution to the designation of over 1100 orphan drugs
- Initiation and organisation of the biennial European Conferences on Rare Diseases (ECRD)
- Initiation and annual coordination of the International Rare Disease Day

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Policy in Action

A Home for ALL Rare Diseases – European Reference Networks

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Patient at the Heart!